Witness Name: Nuala Toman
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UK COVID-19 INQUIRY

WITNESS STATEMENT NUALA TOMAN

ON BEHALF OF DISABILITY ACTION NORTHERN IRELAND

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1. I, Nuala Toman, Head of Innovation and Impact at Disability Action Northern Ireland ('Disability Action'), make this statement on behalf of Disability Action, on matters which are being examined in Module 2C of the Covid-19 Public Inquiry.

Disability Action

2. Disability Action is the largest pan-disability organisation in Northern Ireland. We work with people with various disabilities including physical disabilities, learning disabilities, sensory disabilities, hidden disabilities and mental health disabilities. We are a membership organisation representing more than 300 organisations who are all majority led, directed, governed and staffed by Disabled people.

3. Disability Action operates within the region of Northern Ireland but engages with Westminster and the UK Government on matters of relevance.

4. As a Disabled People's Organisation ('DPO'), we advocate for the rights of d/Deaf and Disabled people (henceforth, 'Disabled people') and provide services which are developed by and for Disabled people. These services include employment support services, human rights and independent advocacy, campaigns, community integration and digital connectivity, transport, information and advice, mental health and wellbeing

and disability specialist support. Our services reach more than 100,000 Disabled people per year.

5. As part of its work, Disability Action is funded by Department of Health NI to support the implementation of the Department of Health NI's Physical and Sensory Strategy. The vision of the strategy is to:

   - Support Disabled people to become well informed and expert in their own needs;
   - Promote health, wellbeing and maximise potential of individuals;
   - Encourage the social inclusion of Disabled people and work to address the stigma associated with disability;
   - Encourage family and person-centred services and the promotion of independent living options;
   - Ensure services are tailored to meet the changing needs of people over the course of their lifetime; and
   - Continue to promote and enable balanced risk taking, as laid out in the Department of Health's Physical and Sensory Disability Strategy and Action Plan 2012-2015.

6. Disability Action supports the Physical and Sensory Strategy by engaging Disabled people in the co-design of health services. Disability Action provides information and advice which assists Disabled people to access health related services and to transition from residential settings to independent living. We provide information and advice services to support Disabled people in their transition from hospital care to home, from school to employment or further education, and from children's to adult health and social care services. This includes guidance on accessing benefits and dealing with discrimination. Disability Action have been involved in the co-design, implementation, delivery and monitoring of key Ministerial directives and Departmental statutory duties including the Mental Health Strategy, the Accident Prevention Strategy, the Reform of Adult Social Care, and the Domestic and Sexual Abuse Strategy. We also support Disabled people in domestic settings, supported accommodation, care homes, and those detained under the Mental Health Act.

7. Up until March 2023 we were funded by the Department of Health to deliver mental health services in the context of the Covid-19 pandemic.

8. The key office-holders at Disability Action are:

- Mel Douglas (Chair) who is responsible for leading the Board, focusing it on strategic matters, overseeing the work of Disability Action and setting high governance standards;
- Andrea Brown (Chief Executive Officer) who provides leadership to Disability Action, is responsible for the organisation's administrative and financial management, developing the organisation's long-term strategy, budget and business plan, and ensuring Disability Action complies with law and regulations;
- Nuala Toman (Head of Innovation and Impact, formerly Head of Policy, Advocacy, Information and Communications) who is responsible for income-generation, identifying opportunities for growth and development, and for leading the achievement and monitoring of impact; and
- Karen Smith (Head of Contracted Services) who is responsible for the management of services delivered by Disability Action, including employment, transport and mobility services.

9. We use the term 'Disabled people' to mean people facing societal barriers due to their impairments or conditions. Our use of the term is recognised by the disability rights movement in the United Kingdom to align with the social and human rights model of disability which acknowledges the fact that Disabled people are disabled by barriers in the environment and in society. The human rights model focuses on the inherent dignity of the human being and places the individual in the centre of all decisions. It recognises the role which society plays in disability. The social model of disability asserts that disability is a form of oppression and socially created disadvantage and marginalisation of people on the basis of disability or impairment [Exhibit NT/1 INQ000396787] and [Exhibit NT/2 INQ000396801].

Disability in Northern Ireland

10. One in four people in Northern Ireland are Disabled. Over half of the population aged 65 or more report having a limiting long-term health problem or disability, whereas 8% of children aged 14 and under report having a limiting long-term health problem or disability For the first time, in 2021, the census included 'Autism or Asperger's syndrome' as a listed health condition and 35,000 people were recorded with this condition. Of this, 19,000 children (or one child in twenty) had 'Autism or Asperger's syndrome' recorded [Exhibit NT/3 INQ000396812].

11. Disability rates in Northern Ireland are much higher than in other countries within the United Kingdom regardless of the type of measure used, with the most common being

self-reported measures of disability or self-reported receipt of social security payments which are disability related. The 2021 Census found that 24% of the population of Northern Ireland report being limited in their day-to-day activities either 'a little' or 'a lot'. This compares to 17% and 22% respectively in England and Wales. These higher rates in Northern Ireland have long been the case [Exhibit NT/4 INQ000396823].

12. Northern Ireland is reported to have the highest prevalence of mental health problems in the United Kingdom, with psychiatric morbidity in Northern Ireland being 25% higher than in the United Kingdom [Exhibit NT/5 INQ000396834], [Exhibit NT/6 INQ000396845] and [Exhibit NT/7 INQ000396856]. The Youth Wellbeing Prevalence Survey 2020 also reported around 25% higher rates of anxiety and depression in the child and youth population in comparison to other UK nations, reflecting a similar trend in the adult population [Exhibit NT/8 INQ000396857]. The legacy of violence and socio-economic factors are frequently cited as key contributors to poor mental health in the Northern Ireland population [Exhibit NT/7 INQ000396856].

13. There are 405 care homes in Northern Ireland and, in 2020, there were 11,808 people living in care homes [Exhibit NT/9 INQ000396858]. We are not aware of any statistics available detailing the number of Disabled people resident in care homes in Northern Ireland. As of 31 March 2023, there were 5,118 persons registered to attend day care services. 50% of those were people with a learning disability, 11% were people experiencing mental health challenges, and 7% were physically Disabled people. On average, 22,575 people received domiciliary care in 2022 [Exhibit NT/10 INQ000396788].

14. Covid-19 decision-making in Northern Ireland regarding Disabled people cannot be seen in isolation and it is important to consider the following:

    (a) the suspension of devolved power from January 2017 to January 2020;
    (b) the resumption of devolved power in the first period of 2020 during the very early stages of the pandemic only to collapse again in February 2022;
    (c) the greater epidemiological connection with the Republic of Ireland as a whole-island pandemic than with the rest of the British Isles;
    (d) the joint health and administrative structures both within Northern Ireland (combining health and care services) and across the whole of the island as provided for under the Good Friday Agreement; and

(e) Northern Ireland's discrete architecture and culture of equality and human rights that is tied to its existence and wellbeing as a post-conflict society and enshrined within the Good Friday Agreement.

Inequalities faced by Disabled people in Northern Ireland

15. In Disability Action's experience, disability inequality is pervasive within Northern Ireland. Disabled people in Northern Ireland are not afforded the same level of equality and protections in comparison with their counterparts in the rest of the United Kingdom and in Ireland. The Chief Commissioner of the Equality Commission for Northern Ireland has stated that the lack of progress to close the gaps in legal protections in relation to equality law has positioned the region in the "dark ages" with respect to equality to such an extent that there is a "serious risk of falling way behind, to not being a developed country" [Exhibit NT/11 INQ000396789]. This is a position which persisted prior to the Covid-19 pandemic [Exhibit NT/12 INQ000396790].

16. Going into the pandemic, Disabled people did not enjoy the human rights set out in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD has still not been incorporated into domestic law. The UNCRPD is an international agreement, drawn up by States with the involvement of Disabled people, which affirms that Disabled people have the same rights as non-Disabled people.

17. In 2016, the UN Committee on the UNCRPD conducted an Inquiry into Disabled people's enjoyment of UNCRPD Articles 19 (living independently and being included in the community), 27 (work and employment) and 28 (adequate standard of living and social protection) within the United Kingdom. The Inquiry report declared that there had been "grave" and "systematic" violations of disabled people's human rights [Exhibit NT/13 INQ000396791].

18. Prior to the pandemic, there were many issues of significant concern for Disabled people in Northern Ireland. These issues included, amongst others, the impact of welfare reform, reduction in social care funding, the impact of Brexit, the implementation of the Mental Capacity Act (NI), health inequalities, and abuse in residential and community settings.

19. Disabled people are more likely than non-Disabled people to live in poverty. Pre-pandemic research suggests that 57% of Disabled children in Northern Ireland were living in poverty compared with 37% of non-Disabled children [Exhibit NT/14 INQ000396792].

20. People living with a learning disability are at risk of poorer outcomes. They are more likely to grow up in poverty, have poor educational attainment, experience social isolation and loneliness, experience mental health difficulties, have poor physical health and a shorter life expectancy [Exhibit NT/15 INQ000396793].

21. Disabled people experience inequalities in accessing suitable housing. Of the 8,531 households who presented as homeless between January 2023 and June 2023, the most commonly quoted cause was 'accommodation not reasonable' and the sub-category of 'physical health/disability' being the cause had the largest proportion of presenters with 57% [Exhibit NT/16 INQ000396794]. Research undertaken by Disability Action and the Equality Commission shows that 8 out of 10 Disabled people believe housing to be inaccessible to them [Exhibit NT/17 INQ000396796]. This means that Disabled people are often trapped in unsuitable housing due to this housing shortage, which includes living in unsafe and unsanitary conditions or having no option other than to enter into residential care.

22. Inequalities in accessing healthcare experienced by Disabled people are well documented and pre-date the pandemic. This includes particular challenges experienced by Disabled people in accessing GP and hospital services [Exhibit NT/12 INQ000396790].

23. The suicide rate is high among d/Deaf and Disabled people, especially those with intellectual and psychosocial disabilities [Exhibit NT/18 INQ000396798]. Mental health services are underfunded and there is poor provision of mental health services, particularly for people experiencing mental health crises and emotional distress [Exhibit NT/19 INQ000396800].

24. Disabled people face barriers in accessing a variety of services, including transport, education, information, digital services, and public office and electoral process. These barriers were identified in the 2011 UNCRPD Report referred to above and Disability Action has seen no changes for the better since this report.

25. Disabled people in Northen Ireland have fewer protections against inequality in comparison with our UK counterparts due to the non-implementation of the Equality Act 2010.

26. There remain several areas of policy, practice and legislation within Northern Ireland which are non-compliant with the UNCRPD. These include: the Mental Health and Capacity Act (2016); inadequate protections against disability discrimination; the continued use of involuntary electroconvulsive therapy; the use of restraint and seclusion in both health and educational settings; evidence of abuse and degrading treatment in institutional settings; inadequate play and leisure facilities for Disabled children; lack of access to appropriate toileting facilities; the underrepresentation of Disabled people in decision-making; and increasing levels of hate crime [Exhibit NT/17 INQ000396796].

The absence of power-sharing arrangements prior to 2020

27. Prior to the pandemic, from January 2017 to January 2020, Northern Ireland did not have a government and was in a state of political limbo. The political crisis disrupted public spending. The breakdown of the Assembly and Executive lasted for three years. The absence of a functioning Assembly and Executive led to major gaps in the governance of Northern Ireland. There was no devolved capacity to formulate policies, introduce Bills, pass legislation or implement policy. Some 67 items of policy were estimated to have been suspended [Exhibit NT/20 INQ000396802]. Without ministers, there was no mechanism to respond to urgent situations or make strategic policy changes. There was also no devolved body to allocate the funding from the Treasury under the Barnett formula to the Northern Ireland departments, or to determine priorities. Decisions could not be taken on other financial matters. There was no one with a democratic mandate to progress issues. Appointments to non-departmental governmental bodies in Northern Ireland's stalled without the required ministerial approval. In the absence of the Assembly, there was also a halt to the work of the departmental scrutiny committees which left a substantial accountability gap. The missing level of devolved government and gaps in governance were strongly criticised by the Northern Ireland Affairs Committee (NIAC) at Westminster in an inquiry into what it termed 'a democratic deficit' [Exhibit NT/21 INQ000396803]. The pandemic emerged in the context of ongoing political stalemate and lack of progress with respect to legislation. For example, Disabled people in Northern Ireland are not afforded the same protections as our counterparts in England and Wales who benefit from protections within the Equality Act 2010.

28. The effect on Disabled people of the 2017 collapse of devolved government was that issues that can take years to gain traction with a functioning government were now without anyone to properly engage with: "Policy decisions relating to Disabled People's lives in NI were ... left in the hands of local civil servants (who, in the absence of

Ministerial authorisation, often felt powerless to act). Meanwhile, politicians in Westminster grappling with Brexit and a myriad of other `bigger' issues, seemed entirely removed from addressing the challenges disabled people and their families in NI were facing" [Exhibit NT/22 INQ000396804].

29. We have seen no evidence to suggest that Northern Ireland Office (NIO) briefed the Northern Ireland Executive Departments or Political Party Leaders in December 2019 and January 2020. The NIO would have had direct engagement with Political Parties at this time through the ongoing negotiations associated with the New Decade and New Approach Settlement which re-established the Executive. This would have presented a prime opportunity to ensure that any incoming Executive was prepared for the pandemic with the potential for consideration for decision making frameworks, implications on particular populations including Disabled people and any financial implications. This did not appear to happen. It is arguable that Disabled people were absent from consideration at this point.

30. Many of the areas of concern regarding the impact of Covid-19 on Disabled people in Northern Ireland are devolved matters, particularly health, transport, education, communities, and employment. There were no devolved ministers to take decisions on planned reforms in health, capital contracts, school amalgamation or workforce planning with severe and cumulative impacts on Disabled people during the time Executive and Assembly were not functional. Therefore, the emergence from political stalemate set a particularly challenging context for decision-making by the renewed Executive during the pandemic. The new Executive faced a backlog in decision-making and severe financial challenges due to a legacy of underfunding in the region [Exhibit NT/23 INQ000396805]. Northern Ireland therefore faced particular constraints in decision-making that may not have been experienced in other regions and which was intensified by the geographic and political peripheralisation of the region from Westminster [Exhibit NT/24 INQ000396806].

31. The pandemic emerged in the context of ongoing political stalemate and lack of progress with respect to legislation. As the new Executive was forming, it was required to respond to an unprecedented pandemic and we are concerned that the newly formed Executive was not adequately equipped to give appropriate considered to Disabled people during the early stages of the pandemic.

32. The resignation of First Minister Paul Givan on 3 February 2022 has, again, resulted in the absence of a clear mechanism to resolve the continuing challenges for Disabled people in accessing services.

33. It was following a three-year period of political instability, and against the background of pervasive and structural disability inequality, that Disabled people entered the pandemic and experienced disproportionate impacts from both the virus and the NPIs introduced to combat it.

The work of Disability Action during the pandemic

34. During the relevant period, Disability Action provided the following specific services to Disabled people in Northern Ireland:

    (a) Information, support and advocacy services, including intensive casework on access to health care and services for Disabled people by phone, email and socially distanced appointments;
    (b) Transportation services for Disabled people to attend healthcare and vaccination appointments;
    (c) A mental health and wellbeing service that provided bespoke counselling to d/Deaf and Disabled people, their carers and families. In response to the decline amongst Disabled people accessing our services, we established the Disability Action Mental Health and Wellbeing Hub. This initially began as a pilot and, following the pilot, we received funding from the Department of Health NI through the Mental Health Support Fund. Through this funding, Disability Action provided 16 sessions of bespoke counselling to 106 Disabled people in the context of the mental health impacts of the pandemic;
    (d) Emotional and practical support for Disabled people facing Do Not Attempt Resuscitation (DNAR) notices, and their families;
    (e) Regular group meetings on Zoom to address social isolation experienced by Disabled people during the pandemic, with more than 2,400 Disabled people availed of these sessions;
    (f) Support to bereaved families of Disabled people who died during the pandemic.

35. Disability Action undertook work to assess the potential and actual impact that NPIs were having on Disabled people during the pandemic. For example, we provided opportunities for Disabled people from various backgrounds to contribute their experiences. These

contributions were submitted orally to the Ad Hoc Review of the impact of Covid-19 on d/Deaf and Disabled people which was hosted by the Assembly All Party Group on Disability, of which Disability Action is the secretariat.

36. We conducted an online survey regarding the experiences of Disabled people, their families and carers during the pandemic. Between 1 and 30 April 2020, we received 404 completed surveys, including over 1300 written statements. Analysis of the data collected included both qualitative and quantitative approaches. A thematic approach was taken to the analysis of text responses, with common themes identified within a report published in September 2020 called '*The impact of COVID-19 on disabled people in Northern Ireland'* [Exhibit NT/22 INQ000396804]. These are referred to in this statement as the 'April 2020 survey' (or the associated 'September 2020 report').

37. From November to December 2021, Disability Action held a series of nine meetings with 431 Disabled people and undertook a survey of 83 Disabled people in Northern Ireland. As a result of this engagement, we published the '*Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland'* [Exhibit NT/25 INQ000396807]. on 22 February 2022. This report is referred to in this statement as the 'February 2022 Alternative Report'.

38. The February 2022 Alternative Report was a broad project intended to shed light on areas of policy, practice and legislation within Northern Ireland which are non-compliant with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The conclusions and findings of the report support Disability Action's view that the failure to incorporate the UNCRPD into law means Disabled people experience inequality and discrimination in all sectors of public life, including healthcare settings, employment, social security and education.

39. The data acquired and used in the February 2022 Alternative Report was commissioned by the Equality Commission for Northern Ireland to review the work on the UNCRPD undertaken in Northern Ireland. As such there is a separate joint report based on this data, entitled *'Progress Towards the Implementation of the UNCRPD in Northern Ireland'* which is referred to in this statement as 'The February 2022 Progress Report' [Exhibit NT/17 INQ000396796]. The Equality Commission for Northern Ireland and Disability Action jointly conclude that there was a range of shortfalls regarding delivery in Northern Ireland relative to the UNCRPD. The purpose of the February 2022 Progress Report was to assist the Independent Mechanism for Northern Ireland, which is a focal point for the

Executive to promote the Rights of Persons with Disabilities, as part of their independent monitoring role. The purpose of the aforementioned February 2022 Alternative Report was to provide a separate, independent report produced by Disability Action.

40. Disability Action also gained information on the experiences of Disabled people through the various services we provided. Our advocacy and casework services provided significant insight into the range of issues faced by Disabled people during the pandemic, and we engaged Disabled people in consultations and evidence sessions to improve services and develop policy, practice and influence legislation. We hosted regular Zoom meetings which allowed our members to discuss the impact of Covid-19 on their lives and which informed our research and policy. Our bereavement services also became a crucial information mechanism to understand the inequality of treatment of Disabled people in healthcare settings during the pandemic, particularly in relation to the inappropriate use of Do Not Attempt Resuscitation (DNAR) orders.

41. Disability Action produced several articles during the pandemic, including:

    (a) Regular updates relating to the Covid-19 pandemic [Exhibit NT/26 INQ000396808]
    (b) 'Reflection: One year on since the first COVID-19 lockdown', published on 25 March 2021 [Exhibit NT/27 INQ000396809]
    (c) 'Where is the Outcry About the Impact of Covid-19 on d/Deaf and Disabled People?', published on 15 March 2022 [Exhibit NT/28 INQ000396810]
    (d) 'Light Up Purple or Wear Purple to mark International Day of Disabled People 2021', published on 18 November 2021 [Exhibit NT/29 INQ000396811]

42. Disability Action also engaged with the Northern Ireland Executive and Assembly in respect of the impact of the Covid-19 pandemic on Disabled people, which we expand upon below.

The impact of the Covid-19 pandemic on Disabled people

Disproportionate number of deaths

43. Disabled people were disproportionately more like to die during the pandemic than non-Disabled people. The Northern Ireland Statistics and Research Agency (NISRA) published an equality group analysis of deaths due to Covid-19 which showed that Disabled people were 42% more likely to die of Covid-19 than non-Disabled people

[Exhibit NT/30 INQ000396813]. UK-wide statistics released by the Office for National Statistics (ONS) on 11 February 2021 revealed that 59.5% of Covid-19 deaths up to November 2020 were of Disabled people (30,296 of 50,999 deaths) [Exhibit NT/31 INQ000396814]. Disabled people made up only 17.2%of the study population, thus starkly illustrating the disproportionate mortality rate faced by Disabled people.

44. The Department of Health in Northern Ireland did not publish data regarding the impact of the pandemic on Disabled people. However, a recent English study, over three waves of the pandemic from 24 January 2020 to 20 July 2022, found that the risk of Covid-19 related death was higher among people with a vision, hearing or both impairments than those without such impairment [Exhibit NT/32 INQ000396815].

45. It is Disability Action's view that mortality differences must be understood in the context of the failure to consider the communication needs of Disabled people when providing public health information. Ensuring everyone in society is able to access and understand public health information during a pandemic is not only a matter of inclusion; it is fundamental as a basic ingredient for the preservation of life. In our view, the absence of accessible health communications left Disabled people more exposed to infection and illness from Covid-19. We expand upon some specific issues regarding accessible communications below.

Impact on healthcare services

46. Through our engagement activities, as well as monitoring changes to our own provision, Disability Action identified early in the pandemic that Disabled people had lost access to essential healthcare and treatments because of the closure of services. The results of our April 2020 survey demonstrated the severe effect this was having on pre-existing physical and mental health inequalities.

47. In our April 2020 survey, Disabled people with pre-existing physical health conditions frequently described the difficulties accessing routine healthcare. For example, one respondent in our April 2020 survey described that *"GP's are not physically seeing patients. Consultants have cancelled appointments",* whilst another was concerned about being cut off from the primary care of their District Nurse, who would *"no longer attend unless the matter is urgent…"* (see page 24). A Disabled respondent to our February 2020 report explained further that, *"Financially, it is almost impossible. The health service is on its knees and support for chronic conditions is gone. If you are lucky enough to get*

a GP appointment, you will likely get a locum who is reluctant to change a treatment. Second class service for disabled people" (see page 25).

48. As well as physical decline, over half (57%) of the respondents to our April 2020 survey explained that disruption to their access to primary healthcare had negative implications for their mental wellbeing.

49. As well as primary healthcare, many Disabled people struggled to access more specialised treatments and therapies associated with their disability. We were told that these services were also critically impacted. For example, one respondent said there was *"No longer any assistance from Allied Health professionals…"* (see page 24 of the September 2020 report). Allied Healthcare Professionals are clinicians who provide ongoing treatments and therapies. They have a range of specialities, such as rehabilitation, nutrition expertise and management of disorders. The impact of changes to the provision of these services during the pandemic could be very severe, depending on the ongoing medical issue at stake.

50. Disabled people faced significant barriers to safe and accessible healthcare compounded by a lack of appropriate transport to and from healthcare facilities, high out-of-pocket expenditure, and stigma and discrimination which further exacerbated healthcare inequalities.

51. Disability Action had significant concerns regarding Do Not Attempt Resuscitation (DNAR) notices after becoming aware of a resuscitation policy in Northern Ireland hospitals that unfairly affected older people. We were alerted to these concerns through our own work on the April 2020 survey and through contact with our bereavement officers, as well as from media reporting. Disability Action Northern Ireland had particular concerns about the message sent by placing a DNAR on a Disabled person's record and its practical effect as lessening the value of a Disabled person's life. The issue of DNARs is addressed in more detailed in the statement we provided to Module 3 of the Inquiry.

52. We were also concerned about the impact of confusing infection prevention and control policies in healthcare settings during the pandemic. In particular, the Public Health Agency guidance *Covid-19: Guidance for Nursing and Residential Care Homes in Northern Ireland* [Exhibit NT/33 INQ000396816] was inadequate in relation to ventilation, PPE, and visitation policies. Our concerns regarding confusing infection prevention and

control guidance is addressed in more detail in the statement we provided to Module 3 of the Inquiry.

Impact on social care

53. Disabled people's access to social care during the pandemic was impacted. In our April 2020 survey, 35% of respondents indicated that the social care support they normally received had been impacted by Covid-19, including 39 people (10%) who described a complete cessation of support they normally accessed. Eleven of these respondents (3%) had reduced or cancelled their social care to protect themselves or loved ones in response to their concerns about hygiene, lack of PPE and contracting Covid-19.

54. A number of people who experienced changes to their social care support also experienced difficulties in communicating with their social worker and lack of alternative support options being made available to them.

55. This placed Disabled people at significant risk of harm. For example, one respondent described having *"no help on ventilator and legally need 3 people to hoist safely",* with another respondent stating that they were "*having to help disabled person shower who takes seizures and he is normally assist x2 and I'm doing it on my own*" (see page 21).

56. Families and carers were cut off from face-to-face support, which was further compounded by the abrupt closure of statutory services, such as day centres, respite care and professional services [Exhibit NT/22 INQ000396804]. The withdrawal of these services left many family carers unsupported and the subsequent slow and reduced opening of these services has prolonged carers' stress and anxiety [Exhibit NT/34 INQ000396817]. The immediate closure of face-to-face services in late March 2020 created unprecedented pressures on the non-statutory sector.

57. The cessation of services, in particular for people with intellectual or psychosocial disabilities, was particularly problematic, with parents, carers and service users left in anxious and unstable situations which caused significant disruption. The cessation of services also placed significant pressure on the voluntary sector to intervene [Exhibit NT/34 INQ000396817].

58. Similar experiences were reflected in our February 2022 Alternative Report. A Disabled person with a long-term health condition who contributed to our research reported the

distress she was experiencing because of the sudden withdrawal of services; *"People with disabilities are being failed by our government during the pandemic, we have no access to day centres and there is not enough support for carers. We are being completely ignored by our Health Minister at every wheel and turn"* (see page 16).

Impact on mental health

59. In our April 2020 survey, 72% of respondents reported that pandemic restrictions were affecting their mental health. The responses had three prevalent sub-themes; feelings of anxiety about contracting COVID-19, being isolated from family and friends, and not being able to access existing support from a General Practitioner or Mental Health Team. Several responses outlined on page 26 of the September 2020 report indicate the decline of a pre-existing condition: *"Weekly Hospital appointments cancelled for mental health…"* and *"Not being able to see my mental health team…"*

60. Barriers in accessing mental health care as a result of Covid-19 also contributed to the institutionalisation of Disabled people. This was both because of the lack of available support in the community and as a result of changes that were made to legislation. The Mental Health (NI order) 1986 and the Mental Capacity (NI) Act 2016 were amended to allow for a relaxation of the requirements in respect of qualifications, training and experience of people undertaking mental capacity assessments, and to ease the time limits for assessment and involuntary detention, with no mechanism for scrutiny. Disability Action was in receipt of funding from the Department of Health to deliver mental health services during this period. Our own specialist employees and contractors reported to us that these legislative changes were resulting in the detention of Disabled people in instances in which they may otherwise have remained in the community. In addition, we heard that Disabled people were detained for a longer period than they would have been prior to the pandemic, causing disruption and distress in their lives.

Accessibility of information

61. Disability Action found that Disabled people were disproportionately impacted by a lack of accessible information. In a public health crisis such as the Covid-19 pandemic, clear information becomes more important than ever. Messages were confused or complicated, which has been difficult for many Disabled people to access and navigate.

62. In our April 2020 survey, people who had difficulty understanding health communications cited a lack of clarity and consistency in such communications. Other times, information could be slow to arrive and, for some, in an inaccessible format.

63. Our 2020 April Survey found evidence of poor communication particularly with regards to the guidance identifying people as ‘clinically extremely vulnerable’, ‘vulnerable’ or ‘at-risk’. In respect of the quality of risk-category communication itself, one respondent explained that *“There’s limited information from organisations, but the advice is somewhat conflicting and vague, due to government guidelines and a lack of clarity on which groups are truly vulnerable…”*“ (page 30). Another respondent told us that they *“have yet to receive any communication re shielding despite one of us being exceptionally high risk…”* (page 22). Indeed, many experiences suggested there were delays in confirming eligibility in risk categories. As a result, many people did not receive their shielding letter when they should have. One individual reported that they had to survive four weeks of lockdown *“without any help”* because they did not receive the shielding letter which would have confirmed their priority status. The impact was that they had to *“pay a fortune for local shop delivery”* (page 34). Another individual reported that the delay in receiving the shielding letter resulted in difficulties accessing medication, and the leaflets providing information about how to access help to collect medication did not provide for the appropriate level of support. However, that individual was told by volunteers that in order to receive further help to access their medication, the volunteers would need the *“letter as proof of my condition and my needs.’* (page 34).

64. At the time of our survey in April 2020, only ninety-six respondents had received a shielding letter. In our summary section, at page 44, we point to academic reports which reveal differences between government lists and GP records and the resulting “grey area” that emerged in terms of shielding such that some individuals did not receive shielding letters when they should have. We believe this difference may explain the discrepancies that subsequently arose. Overall, we summarise that the impact on Disabled people of these ”grey areas” surrounding risk-category and vulnerability was widespread confusion and uncertainty, particularly in terms of what qualifies a person for support, leaving people uncertain of where to turn.

65. In terms of broader public health communications and guidance, there are usually two main factors in relation to Disabled people accessing information: Disabled people are less likely to be able to access the information than the general population, and, depending on conditions and impairments, they are less likely to be able to understand

and/or follow it without appropriate adjustments. This leaves Disabled people more vulnerable to infection and illness and more likely to further the transmission of the virus.

66. The initial failure to have sign language interpreters available in the daily briefings to disseminate information about social distancing and preventative measures was *"further alienating"* to d/Deaf and Disabled people [Exhibit NT/35 INQ000396818].

67. Outside our own work, we were aware of the 2020 study from ARC (NI), *A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland* [Exhibit NT/34 INQ000396817] which analysed guidance produced by public health agencies in the UK and within Northern Ireland. The study found that initial guidance from government agencies was not attuned to the needs of persons with learning disabilities and their living situations; particularly for those in supported living arrangements rather than residential homes. Pages 19-22 of the study refer to the fact that, within Northern Ireland, there were numerous bodies issuing guidance in relation to settings which provide care for people with learning disabilities. From May 2020 onwards, as lockdowns were being eased, more specific guidance started to appear, but also previous guidance was being revised in the light of experiences, which compounded uncertainty around the 'proper' procedures that different agencies within Northern Ireland were recommending. This was especially so when the guidance had to be interpreted and applied to particular groups (such as people with learning disabilities) in service settings which supported them. Indeed, different service settings which support people with learning difficulties often have very different approaches and ways of working. For example, there are often vast differences in work practices between supported living environments compared with nursing and residential care homes. This area of the report accurately describes a sense of confusion regarding public health guidance that emerged, and which Disability Action picked up on, during the time.

68. Due to concerns about the inadequacy of information being provided to Disabled people during the pandemic, we also set up a 'Coronavirus Updates' page on our website. We updated this page regularly with news, information, signposting and advice for our members and all Disabled people and their carers.

Access to food and medicine

69. Over half of the respondents to our April 2020 survey indicated they had experienced disruption in accessing food of medicine, with further respondents stating that, although they were managing at the time, they had concerns about future access to food and medicine.

70. Respondents described how home deliveries of food and priority status were problematic: *"Ran out of food today. Managed to get on Tesco's vulnerable list, but won't be delivered for three days"* (page 27). Disabled people experienced practical challenges in going shopping. For example one respondent was *"blind so shopping for food and other items is a huge challenge right now with social distancing"* (page 28).

71. Thirty-nine respondents to our April 2020 survey described that accessing medication was becoming problematic. This related to delays in receiving medications from pharmacies; individuals reported that it was *"Slow to get medicines…"* and also issues in relation to supply shortages; one respondent reported that *"Medicines frequently out of stock, went six days without pain relief…"* (page 28). One clear impact of being unable to access treatments from pharmacies was the worsening of pre-existing physical health conditions. This was particularly the case for pain and discomfort: *"I have no meds for three days and apart from the pain which is horrendous I now have to suffer excruciating withdrawal symptoms…"* (page 24).

72. Difficulties accessing food and medication were reported to decrease self-reliance: One respondent said that *"Loss of independence and relying on others for basics of living like food and medicine. I have found this loss of independence very challenging…"* (page 29). Privacy was also a concern, as some people were forced to rely on others to collect medicines from pharmacies for them; *"Because I cannot go to pharmacy it means family know what my medication is…"* (page 29).

Collection of data in relation to Disabled people

73. In Disability Action's experience, there was little work done to collect figures in relation to the numbers of Disabled people contracting, becoming seriously unwell or dying from Covid-19 until far too late.

74. It was only in December 2021 that the assessment of the impact of Covid-19 on Disabled people was made available when the Northern Ireland Research Statistics Agency published its report analysing Covid-19 deaths in the first wave of the pandemic in

relation to equality group, health and socio-demographic characteristics [Exhibit NT/30 INQ000396813].

75. This publication demonstrated that, after adjusting for age, sex, area of residence, socio-demographic characteristics and health, there was a 48% higher risk of Covid-19 mortality for persons self-reporting having a disability at the time of the 2011 census compared to non-Disabled people, and a 40% higher risk for non-Covid-19 mortality.

Engagement with the Northern Ireland Executive and Assembly

76. On 22 April 2020, Disability Action wrote an open letter to Health Minister Robin Swann, Chief Medical Officer Dr Michael McBride, and Chief Social Worker Sean Holland, outlining the need for an ethical framework for the treatment of Disabled people [Exhibit NT/36 INQ000396819]. This letter arose out of concerns that Disabled people were not receiving equal access to healthcare and were not being consulted in respect of guidelines being produced during the course of the pandemic.

77. On 29 April 2020, the Health Minister responded and endorsed the guiding principles we had set out in our letter, [Exhibit NT/37 INQ000396820].

78. We were subsequently invited to meet with a sub-group of the NI COVID-19 HSC Clinical Ethics Forum to discuss the issues raised in our 22 April 2020 letter. On 6 May 2020 we attended a meeting, and we subsequently provided input into a draft framework [Exhibit NT/38 INQ000396821]. The finalised guidance reaffirms non-discriminatory and ethical medical treatment [Exhibit NT/39 INQ000396822].

79. Despite the publication of the Ethical Advice and Support Framework, Disability Action's concerns about the experiences of Disabled people increased as the pandemic progressed.

80. On 1 February 2021, Disability Action attended a meeting of the Northern Ireland Assembly All-Party Group on Disability, which included updating on progress relating to the disability strategy [Exhibit NT/40 INQ000396824].

81. On 11 May 2021, the Northern Ireland Assembly All-Party Group on Disability met again to discuss the development of a new disability strategy [Exhibit NT/41 INQ000396825] and [Exhibit NT/42 INQ000396826].

82. On 25 November 2021, Disability Action wrote to the Health Minister Robin Swann to request an urgent meeting due to concerns about the disproportionate number of Disabled people dying from Covid-19 as well as concerns about access to essential health and social care [Exhibit NT/43 INQ000396827]. We said "[a]lmost two thirds of people who have died due to coronavirus were d/Deaf and Disabled People. Research undertaken by Disability Action regarding the experience of disabled people during the pandemic has shown that health and social care services for disabled people had experienced significant disruption and that many disabled people have experienced a decline in physical and mental health. This was a result of the removal and reduction in access to key services and support. Our research also showed that disabled people had challenges in accessing medication and food". We called on the Department of Health to consider rights under the ECHR and UNCRPD in its approach to dealing with Covid-19 and to provide reassurance to Disabled people that they would have equal access to hospital treatment, health and social care services.

83. On the same date, we also wrote to members of the Executive to request an urgent meeting to discuss these issues. Please see correspondence with:

- The First, Deputy First and Junior Ministers [Exhibit NT/44 INQ000396828]; and
- Paula Bradley MLA [Exhibit NT/45 INQ000396829].

84. In November and December 2021, we sent emails to several members of the Assembly requesting meetings to discuss concerns Disability Action had regarding the lack of engagement with d/Deaf and Disabled people with respect to Covid-19 planning, as well as our concerns about the disproportionate mortality rate experienced by Disabled people and the forthcoming Disability Strategy. These included Robbie Butler MLA [Exhibit NT/46 INQ000396830], Colm Gildernew MLA [Exhibit NT/47 INQ000396831], Pádraig Delargy MLA [Exhibit NT/48 INQ000396832], Rachel Woods MLA [Exhibit NT/49 INQ000396833] and Sinead Bradley MLA [Exhibit NT/50 INQ000396835]. We also requested a meeting with Richard Pengelly from the Department of Health NI [Exhibit NT/51 INQ000396836].

85. On 9 December 2021, Paula Bradley cancelled a meeting with us which had been scheduled for the following day [Exhibit NT/52 INQ000396837].

86. On 13 December 2021, we received a response from the Minister of Health which acknowledged the disproportionate impacts of the pandemic on Disabled people and the "immediate work" that needed to be done [Exhibit NT/53 INQ000396838]. Unfortunately, Mr Swann did not feel that a meeting with us at that juncture would be helpful.

87. On 13 December 2021, Disability Action met with Gerry Carroll MLA and sent a follow-up email providing notes on the pandemic, requests Disability Action had of the Department of Health and attaching our feedback on the Disability Strategy [Exhibit NT/54 INQ000396839] and [Exhibit NT/55 INQ000396840]. We sent similar emails to Pádraig Delargy MLA [Exhibit NT/56 INQ000396841] Robbie Butler MLA [Exhibit NT/57 INQ000396842] and Kellie Armstrong [Exhibit NT/58 INQ000396843].

88. On 20 December 2021, we wrote to the Chair of the Health Committee, Colm Gildernew to note that we had previously written to the First and Deputy First Ministers, Junior Ministers, the Minister of Health and the Department of Health raising concerns about the impact of Covid-19 on d/Deaf and Disabled People [Exhibit NT/59 INQ000396844]. We informed him that we had yet to receive assurance that the matters which we raised were being appropriately addressed. We reiterated our concerns about the removal and reduction in access to key services for Disabled people and asked to engage with the Health Committee. We did not receive a response to that letter.

89. On 4 January 2022, we were invited to attend a meeting with the Executive Office to discuss ongoing work in relation to the wearing of face masks [Exhibit NT/60 INQ000396846]. Following this meeting, we arranged an open meeting on 11 January 2022 to gain feedback from d/Deaf and Disabled people regarding regulations with respect to mask exemptions. This meeting was attended by Jane Holmes from the Executive Office [Exhibit NT/61 INQ000396847]. On 12 January 2022, we prepared a response to our engagement with the Executive regard face covering exemptions [Exhibit NT/62 INQ000396848].

90. On 27 January 2022, we received correspondence from the First Minister and Deputy First Minister accepting the request for a meeting made on 25 November 2021 [Exhibit NT/63 INQ000396849]. This meeting did not proceed due to the resignation of the First Minister.

91. On 1 February 2022, Disability Action attended the Annual General Meeting of the Northern Ireland Assembly All-Party Group on Disability [Exhibit NT/64 INQ000396850].

92. On 3 February 2022, Disability Action prepared a response to the Covid-19 recovery plan [Exhibit NT/65 INQ000396851].

93. On 23 February 2022, the Northern Ireland Assembly All-Party Group on Disability hosted an informal review of the impact of Covid-19 on d/Deaf and Disabled people, which involved d/Deaf and Disabled people sharing personal testimonies regarding their experience of Covid-19 [Exhibit NT/66 INQ000396852].

94. Michelle O'Neill visited Disability Action on 13 April 2022 and engaged with Disability Action on the impact of Covid-19. While this meeting was positive and helpful, it was not an Executive Meeting as Michelle O'Neill was not in a Ministerial position at the time due to the resignation of former First Minister Paul Givan who resigned on 3 February 2022 in protest at the lack of progress made within negotiations between the UK Government and EU with respect to the Northern Ireland Protocol.

95. Unfortunately, our calls for the Executive and Assembly to both engage with us as a representative organisation and to publicly acknowledge the impact of Covid on d/Deaf and Disabled people were left unanswered.

96. Disability Action was not party to any informal or private communications, such as text messages or WhatsApp groups, with Ministers and/or civil servants.

Engagement with the UK Government

97. Disability Action's key focus during the pandemic was on Disabled people in Northern Ireland, given the devolved nature of key delivery areas such as health and social care. Our engagement with the UK Government was therefore limited.

Cooperation with the Republic of Ireland

98. Disability Action was not substantively involved in any work or cooperation with the Republic of Ireland regarding the impact of Covid-19 on Disabled people.

Key challenges and lessons learned

99. Disability Action considers that, on the evidence available, the Secretary of State for Northern Ireland, the Northern Ireland Office and Executive departments failed to undertake appropriate screening of the cumulative impacts of NPIs and failed to consult

Disabled people (including Disability Action) contrary to section 75 and Schedule 9 of the Northern Ireland Act 1998. There were complex interdepartmental programmes as well as programmes with interdepartmental impacts which had a severe impact upon Disabled people. The failure to address these matters at the level of the Executive resulted in no single Department or Minister having responsibility for Disabled people and, as a result, Disabled people fell through the gaps.

100. It is clear to Disability Action that the Executive did not have sufficient regard to the needs of Disabled people in relation to the effects of NPIs and any steps which may be taken to mitigate those effects.

101. Initial guidance from Government agencies at the beginning of the pandemic were not attuned to the needs of Disabled people, in particular those with learning disabilities. The guidance from different agencies regarding support for people with learning disabilities, especially those living in supported living arrangements rather than residential homes, was contradictory and had not been developed with organisations and personnel with the necessary experience as [Exhibit NT/34 INQ000396817].

102. The 2020 report, 'An Affront to Dignity, Inclusion and Equality' highlighted that there had been a failure to provide reasonable adjustments to Disabled people during the pandemic which led to widened inequality. The report concluded that the Government failed to take appropriate steps to include Disabled people in planning across all policy areas in response to the pandemic [Exhibit NT/67 INQ000396853]. Research conducted by Disability Action found that eight out of ten Disabled people did not feel they had the opportunity to be involved in the planning response to Covid-19. The same proportion of Disabled people also felt that planning did not effectively protect Disabled people [Exhibit NT/17 INQ000396796].

103. A further challenge was in relation to the publication by the Executive of the Covid-19 Recovery Plan in August 2021 [Exhibit NT/68 INQ000396855]. The Plan was published following a limited one-week consultation with a small number of disability and other organisations, including the Equality Commission for Northern Ireland. It is our understanding that only one DPO had been consulted and that their views on the Covid Recovery Plan were not reflected in the final publication.

104. The lack of co-production with Disabled people in creating the Recovery Plan is evident in its content. Disability Action consider that one of the significant failings of the

Recovery Plan is that it mainly focuses on aspirational statements intended to describe the general direction of travel to achieve economic, health and social recovery. The Plan does not contain detailed consideration of equality issues or a human rights perspective on recovery. The Plan draws attention to a wide range of existing strategies, policies and programmes published prior to the pandemic and takes a medical model approach (which addresses clinical vulnerability) rather than a human rights-based approach. Disability is only referenced once and the Plan lacks actions or quantifiable outcomes to address issues faced by d/Deaf and Disabled people because of the pandemic.

105. The lack of consideration of Disabled people both in preparing for and during the pandemic is apparent from, for example, the manner in which Disabled people were overlooked or treated as an afterthought in the educational provision for children with special educational needs, the provision of personal protective equipment in social care and the lack of the initial inclusion of sign language in government announcements.

106. Disability Action considers that the Executive should have made the following decisions differently:

(a) Disabled people should have been properly included in planning and decision-making, including through membership of any government institutions and associated bodies that were intended to advise on, develop and implement policy during a pandemic;
(b) The Northern Ireland Executive and the Irish Government should have considered ways in which to treat Ireland as a single epidemiological unit. Guidance and frameworks should have been provided and agreed to achieve this in a similar manner as the Fortress Ireland approach adopted for Bovine Tuberculosis;
(c) Frameworks should have been in place to facilitate the safe delivery of health and social care;
(d) Measures should have been put in place to ensure that Disabled people had proper access to food and medicines;
(e) Consideration should have been given to the safe delivery of education, including access to appropriate equipment to support remote learning where required;
(f) The Police Service of Northern Ireland should have been properly briefed regarding the safe management of Disabled people. Ethical considerations should have been considered in the implementation of spit and bite guards;

(g) A strategic approach to shielding should have been implemented with a clear and consistent mechanism for the identification of Disabled people and a proper system of support should have been established;

(h) Accessible communication should have been implemented across the Executive as a minimum to ensure that no one is excluded from accessing public health information; and

(i) Specialist structures concerned with risk management and civil emergency planning should have allowed for proper consideration of societal, economic and health impacts on Disabled people in light of pre-existing structural inequalities and discrimination in line with section 75 of the 1998 Act.

Recommendations

107. In line with Article 4(3) of the UNCRPD (General Obligations), the Executive should establish a mechanism to consult with and actively engage with Disabled people (including Disabled children) in planning and delivering the next phase of its response to Covid-19. It is essential that the needs of Disabled people are addressed within every plan and change in regulations.

108. DPOs such as Disability Action should be properly funded to ensure that there is effective co-production and design of policies affecting Disabled people to deal with both the ongoing effects of the pandemic and the necessary preparations in the event of the emergence of a vaccine-resistant strand of Covid.

109. Regarding vaccination, roll-out strategies should give priority to Disabled people and their support networks. Vaccination centres must be accessible for people with a range of disabilities. Disability accessibility audits should be undertaken to ensure that all vaccination centres have ramps or step free access and are fully accessible. Outreach should be undertaken to enable Disabled people, and particularly those with sensory or intellectual disabilities to access vaccination. This should include home visits for people unable to reach vaccination centres and transportation services. The Executive should also conduct multi-stakeholder consultations on the development of a disability inclusive vaccination strategy which should include DPOs, Disabled people, civil society and government representatives.

110. The voluntary and community sector in Northern Ireland has made a major contribution to transforming social care provided to people with learning disabilities, notably towards a more person-centred and community-based approach. Their

experience and expertise qualify them to be full partners with statutory services in the process of recovery and renewal of services post-Covid-19 in line with the aspirations for the transformation of adult social care. That partnership should also extend to d/Deaf and Disabled people themselves. Assurances also need to be given regarding continuity of contracts to ensure the financial stability of the services provided by the non-statutory sector.

111. The Executive should properly resource DPOs to become partners in roll out information campaigns that reach the most marginalised populations and ensure that messages are clear, inclusive, and accessible.

112. The Executive must take account of Articles 10 (Right to Life) and 25 (Health) of the UNCRPD in its approach to dealing with Covid-19, by providing Disabled people, older people, and carers with reassurance that they will have equal access to hospital treatment, health, and social care services.

113. The Executive should involve Disabled people in economic planning as the disability employment gap is wider in Northern Ireland when compared with other regions of the United Kingdom.

114. The report by ARC (NI) [Exhibit NT/34 INQ000396817] recognised that it is essential that contingency plans are put in place for further Covid-19 surges or similar emergencies. The safety of d/Deaf and Disabled people should be a core consideration and their emotional and social well-being prioritised in the planning of services.

115. The Executive should prioritise and resource the Disability Strategy and ensure it provides a clear plan to mitigate existing inequalities magnified by the impact of the pandemic.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed:

Personal Data

Dated: 19.01.24